

Social Work/Maatskaplike Werk Vol 53 No 4; Issue 4

<http://socialwork.journals.ac.za/pub>

doi:<http://dx.doi.org/10.15270/52-2-594>

#### CHALLENGES EXPERIENCED BY SURVIVORS OF TRAUMATIC BRAIN INJURIES AND THEIR FAMILIES

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While there have been numerous international publications on the challenges experienced by survivors of traumatic brain injury (TBI) and their families, little has been published in South Africa (Alexander, Fuller, Hargovan, Clarke, Muckar, & Thomson 2009). For this study, conducted at Headway in Johannesburg and involving six survivors of brain injury and six family members, data were collected through qualitative in-depth interviews. Transcriptions generated from 12 in-depth interviews with purposively selected survivors of TBI were analysed, using a thematic content approach. Key findings are used to argue that employable survivors and families of brain injury require increased opportunities for sheltered employment.

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## **INTRODUCTION AND PROBLEM STATEMENT**

Traumatic brain injury (TBI) is a major public health problem, especially among male adolescents and young adults between the ages of 15 and 24, among people of both sexes who are 75 years and older, and also among children who are 5 years and younger (National Institute of Neurological Disorders and Stroke, 2002). TBI is a public health problem because the consequences of the brain injury impact on the wellbeing of the family of the injured person in several ways.

This article reports and discusses findings from a case study of 12 families directly affected by TBI. A qualitative methodology with purposive sampling was employed. Data were collected through semi-structured individual interviews and focus groups. The data were analysed thematically. The authors argue that there is minimal or complete lack of support for TBI survivors and their families. Families and communities are to a large extent not even aware of the preventative and rehabilitative resources available for brain injury survivors.

## **LITERATURE REVIEW**

This short literature review begins with definitions of traumatic brain injury in order to demonstrate the differences between TBI and other injuries. The rest of the review is concerned with literature on the impact of TBI on survivors and their families, which is the focus of this study.

According to Silver, McAlister, Yudofsky and Arlington (2008), TBI is a traumatically induced structural injury and/or physiological disruption of brain function as a result of an external force that is indicated by new onset of at least one of the following: any new loss or decreased level of consciousness, any loss of memory of events immediately before or after the injury, any alteration in mental state at the time of the injury (confusion, disorientation, slowed thinking, etc., also known as alteration of consciousness) or neurological deficits (weakness, loss of balance, change in vision, praxis, paresis/paraplegia, sensory loss, aphasia etc.). The National Institute of Neurological Disorders and Stroke (2002) defines TBI, also known as Acquired Brain Injury (ABI) or simply Head Injury, as a sudden trauma which causes damage to the brain; this damage can either be focal (confined in one area of the brain) or diffuse (involving more than one area of the brain). Tagliaterri, Compagnone, Korsic, Servadei and Kraus (2006) state that brain injury is different from, for example, a broken limb or punctured lung because the latter are limited to physical changes or dysfunctions, but brain functions such as cognition are not affected. TBI is more critical because our brain defines who we are and the consequences of damage to the brain will affect all aspects of our lives including our cognitive functioning, physical mobility, emotional and

psychological stability, personality and mental state. It is important to understand that brain injuries do not heal like other injuries (Thompson & Logue, 2006). These definitions indicate that the extent of a brain injury varies from individual to individual and thus the extent to which an individual's psychological, emotional, physical and cognitive functions are affected also varies from mild to moderate to severe.

The impact of TBI on a survivor's family also varies in relation to the severity of the injury and the socio-economic situation of the family. Norman, Matzopoulos, Groenewald and Bradshaw (2007) state that lack of knowledge and misconceptions about brain injuries appear to be common among family members. Limited knowledge can hinder the recovery of brain-injured family members as can lack of information about available support structures and services (Thompson and Logue, 2006). Families generally lack such knowledge and this in turn hinders the recovery of brain-injured survivors, as well as the ability of the family to access services or the support structures they might need.

One of the aims of this paper is to contribute to knowledge of how TBI survivors and their families can be supported.

## **RESEARCH QUESTION AND GOAL**

A research question is often used to focus exploratory studies as it refers explicitly to the problem that is to be investigated. The following research question guided this study: What are the challenges experienced by survivors of brain injuries and their families?

The goal of the study was to explore the challenges experienced by survivors of brain injuries and their families.

## **RESEARCH METHODOLOGY**

Qualitative research is a broad approach in social research that is based upon the need to understand human and social interaction from the perspective of insiders and participants in the interaction (Greenstein, Roberts & Sitas, 2003). Methodology refers to the way that the researcher may go about practically studying whatever he or she believes can be known (Terre'Blanche and Durrheim, 1999). This study adopted an exploratory methodology, there are many advantages associated with the use of the exploratory design. Firstly, the separate phases make this design straightforward to describe, implement and report; secondly, although this design typically stresses the qualitative aspect, the inclusion of a quantitative component can make the qualitative approach more acceptable to an audience that is more inclined towards quantitative approaches (Creswell, 2006). A purposive sampling enabled the researchers to explore the challenges experienced by brain injury survivors and their families. A total of 6 participants who are TBI survivors who sustained injuries between 1995 and 2016, and 6 immediate family members, technically referred to as caretakers, were interviewed. Data were collected through in-depth interviews, guided by an interview guide. According to Greenstein *et al.* (2003), in-depth interviews with an interview guide indicate a clear list of issues to be addressed and questions to be answered, but there is more flexibility around the sequence in which the questions are asked. The interviews were then transcribed and the data were content (thematically) analysed according to the

nine steps of Creswell's process for qualitative data analysis in (Schurink, Fouché & De Vos, 2011). The trustworthiness of the findings was ensured through member checking and reflection (Lietz, Langer and Furman, 2006). Data saturation was reached after 12 in-depth interviews.

Ethical considerations, specifically the avoidance of harm, informed consent, non-violation of research participants' privacy, as well as anonymity and confidentiality, were taken into account (Babbie and Mouton, 2001; Welman, Kruger and Mitchell, 2005). Before data collection was undertaken, the authors received ethical clearance from the Research Ethics Committee of the University of the Witwatersrand. Prior to undertaking this study, the primary researcher was an honours student at the University of the Witwatersrand.

## SAMPLING

The research findings are outlined in two sections, namely profile of the participants, and a presentation of the main themes that emerged. For the purpose of this paper, quotations from the participants are presented verbatim. However, comments made in any indigenous language common in the area where Headway is located were translated into English in some instances.

The participants in this study consisted of six attendees (three females and three males) to be able to get perspectives from both genders and their family members/caregivers (either mother, son, sister, daughter etc.). The attendees ranged in age from 30 to 65 years old and suffered a brain injury from an average period of 3 to 15 years. All attendees are survivors of brain injuries, with one having been caused by an illness, one through a motor vehicle accident (MVA), one was assaulted, and the other three the injury was caused through a stroke. All participants resided in the Alexandra community with their families at the time of the interviews. All of the attendees had two factors in common, namely they are survivors of brain injuries, and attend Headway rehabilitative services. The interviews contributed varying amounts of information to the emerging themes in this study.

**TABLE 1**  
**PROFILE OF PARTICIPANTS**

DEMOGRAPHIC FACTOR	SUB-CATEGORY	NUMBER
Participants (attendee) information		
Gender	Female Male	3 3
Age	30-39 40-49 50-59 60-69	3 (2 males) (1 female) 1 (1 female) 0 2 (1 male) (1 female)
Race	Black White	6 (3 females) (3 males) 0
Ethnicity	Zulu Sotho Xhosa	3 (2 females) (1 male) 1 (1 male) 1 (1 female)

	Tshwane	1 (1 male)
<b>CAREGIVER INFORMATION</b>		
Relationship to attendee	Mother	1
	Father	0
	Sister	3
	Brother	0
	Daughter	0
	Son	2

## RESEARCH FINDINGS AND DISCUSSION

Themes which emerged are presented as follows:

- Challenges experienced by survivors of traumatic brain injuries and their families/caregivers;
- Stigma and stereotypes associated with traumatic brain injuries or disabilities in communities;
- Perceived roles of communities and the government to improve the lives of people living with brain injuries;
- Effectiveness of the rehabilitative services provided at Headway.

As similar themes emerged for both the brain injury survivors as well as the brain injury family survivors, the findings are presented together.

### Theme 1: The challenges experienced by survivors of traumatic brain injuries and their caregivers

This theme is divided into two parts: (1) the challenges experienced by survivors of TBIs and (2) the challenges experienced by caregivers/family members of the individuals who are survivors of brain injuries. When participants were asked about the challenges that they experienced after they suffered a brain injury, they mentioned a few critical areas, namely emotional, psychosocial, cognitive, communication, speech and language, and physical challenges. Each is discussed below..

#### Emotional challenges

When individuals were asked to share some of the challenges that they experienced as survivors of brain injuries, they often mentioned that they found it hard after the injuries to be able to accept that “this” has happened. They indicated that it takes some time to be able to come to a state of acceptance that life has changed. Participant 3 said:

*“The biggest challenge I had was when I was released from the hospital and I realized that I could not stand up or even walk and I really struggled and still struggle even now having to accept the fact that my life has changed and it took me about eight months to learn how to walk again and to be able to find my balance and to realize the fact that this thing is serious and it is not a joke.”*

This is one of the emotional challenges experienced by the majority of the participants. They expressed that the realisation that their lives will never be the same was the hardest to accept. People with brain injuries experience loss of self in various forms. Although they may successfully use strategies to minimise a sense of loss, in most cases individuals with traumatic brain injuries find it difficult to develop a clear sense of how they have become as they are and what they can or cannot do, which makes it very difficult for them to be able to accept the changes ahead (Pollack, 1994).

Participants also shared that one of the reasons behind the difficulty of accepting the changes associated with brain injury are incessant questions such as “*Why me?*” “*Couldn’t it have happened to someone else?*” and “*What did I do to deserve this?*” These questions would often make them feel that they are in a situation they do not deserve to be in. All these emotional difficulties resulted in feelings of sadness, anger, self-blame. More often than not, participants indicated that they feel like giving up on life.

TBI survivors often have a tendency to compare their present condition with their past in many aspects of their lives (Nochi, 1998). This can be noted from one participant’s answer when he explained that: “*I used to be very independent in their past and used to have occupations whereby there was an independent income that was to help them sustain their daily needs.*”

Another participant said: “*I use to be an active sports member of society, but now it is difficult*”, while some viewed it as impossible to be able to be the same person.

Severe brain damage can lead to survivors’ loss of memory. This loss of memory affects the survivors’ understanding of their present selves, leaving them struggling to accept their current self (Nochi 1998). This can also lead to constant comparisons by survivors as to the individuals they used to be before the brain injury, often based on their prior capabilities.

During the interviews participants would constantly mention that they used to do some things that they can no longer do because of the brain injury. Participant 4, who suffered a traumatic brain injury as a result of a car accident in 2004, had the following to say: “*I used to be this and that*”. Participants would often use metaphors to try and minimise the loss of self by explaining their functional changes using terms such as “*ngiyisigole*” (someone who is not capable of doing things for him/herself) or “*ngiyahlanya*” (crazy person).

This is an impact of the emotional rollercoaster they experience stemming from the realisation that they cannot pursue some of their dreams either career- or family-wise, or just have an opportunity for self-exploration. According to Taylor (2000), one of the strategies against the loss-of-self-by-comparison is to preserve the hope of recovery; the theme of hope seems to be common especially during the later stages of recovery from traumatic brain injury.

It proved difficult for the individual with a brain injury to deal emotionally with the challenges of living with a brain injury. Most of the participants expressed having

difficulties in coming to terms with the new change of their social circumstances. The changes emanating from TBI also have a huge impact on the family members. Similarly, family members also go through a difficult process of coming to accept the change and to adjust. Participant 8, who is a relative to a TBI survivor had the following to say:

*“There were a lot of changes because you are always thinking and complaining internally, asking yourself what cause her to be the way that she is now. And you ask yourself why didn’t the doctors see that there was something wrong with her because even as a child she was someone who was always consistently sick and you ask yourself why didn’t they notice that something was really wrong as she also had a heart problem and I would always bring her to the clinic as a child as she would get sick consistently. But doctors were unable to really see that there is something wrong with her after she suffered a stroke and by then it was too late for anything to be done.”*

### **Psychosocial challenges**

According to Taylor (2000), social competence involves social perceptions and the ability to make social judgements. After the experience of a traumatic brain injury individuals may experience or exhibit poor social/behaviour or sensitivity to others, and engage in inappropriate or disinhibited behaviours; this has the ability to affect their integration into the community again. But on the other hand, lack of social contact can also affect self-esteem and consequently life satisfaction. Most of the participants did say that after their brain injuries they found it difficult to go into the world and make friends.

*“No I changed a lot. Even now I realise that when days are dark, friends are few and this is hard for me, I am only free when I am here at Headway, but when I go home, I have no one. My friends are gone, my family does not understand me, it makes me sad and people will treat like you are nothing, but I know things will change one day and even now people are taking advantages.”*

The loss of friendship was frequently mentioned by participants in the age group 30 to 33 years, more so than the older attendees or survivors of brain injury, but they were also the individuals who had recently experienced a traumatic brain injury within the past five years. Therefore, often supported more by family rather than friends, individuals with a traumatic brain injuries find it difficult to make friends and to interact with other individuals outside of their immediate environments; this has a high probability of leading to social isolation for the survivor.

Loneliness is a major issue, with 50% of the respondents in this study having limited if any contact at all with friends. Participants isolate themselves, because they feel as if they are not understood. This could be because they are being isolated by their own friends, families, or communities, since they are thought of as different. The lack of social skills, a lack of interest or inability to initiate social behaviours and personality change are all identified as contributory factors to the social isolation of survivors of traumatic brain injury (Nochi, 1998).

Psychosocial challenges are not only limited to the attendees or the survivor of a brain injury, but are also faced by family members, more specifically the primary caregiver. Because of the amount of time that they dedicate taking care of their loved ones, they have to restructure their entire schedules so to be able to accommodate the survivor's needs. What this means is that they will then have to adjust some of their social activities, such as going to church or the shops, and even more seriously, quit work to be more available in the home. The mother of Participant 3 said:

*“Ohhhhoooo by the time my daughter got a disability I was already retired but I still did experience other challenges despite my availability like the fact that I couldn't go to the shops or to church and leave her alone. But God spoke to me and told me that there is nothing to fear, if something is meant to happen it will happen regardless of whether I am there or not, eventually I had to learn to leave her alone with the hope that she will be fine and I learned to go to church and the shops again and I would come back and she would be fine every single occasion when I came back.”*

The impact of a traumatic brain injury affects the family and the caregivers as much as they affect the individual, but the extent to which families are affected often goes by unnoticed. Being able to accommodate the needs of an individual means that one would need to make adjustments to their own personal schedules and take care of a loved one, which at times might lead them to neglect their own needs. Family members are just as affected by the effects of brain injury as the attendee.

### **Cognitive challenges**

There are various cognitive challenges that were highlighted during the interviews with participants in the study. According to Miller (1993), cognition is the act of knowing or thinking; it includes the ability to choose, understand, remember and use information. After a TBI it is common for people to have problems with attention, concentration, speech and language, learning and memory, reasoning, planning and problem solving. Participant 1 mentioned loss of memory and an inability to remember events and details of specific information shared with her as one of the challenges experienced after her brain injury.

*“My memory was also bad, you would tell me something and I would forget now in few minutes time and somebody would come to my house and say he's looking for my father cause my father was a draughtsman, cause people will come and say we are looking for your father at the house, if they came in the house I will ask him what he wants me to say to my father but when he walks through the door I had forgot what he was saying and my sister children would always try to help me remember things and that helped me a lot, they would ask me things like mam'ncane (auntie) what is this? And that helped me a lot towards making strong of my memory.”*

While some participants did say that after the brain injury it became harder to concentrate on activities, they could eventually engage in activities that required longer periods of concentration. This aspect could be attributed to the fact that rehabilitation



activities were of benefit. According to the American Association of Health and Disability (2009), as time progresses and with training there is the potential that during the rehabilitation process survivors of brain injury could improve some of these cognitive abilities.

### **Communication, speech and language**

Communication may also be difficult for a person with TBI. It is common for a person to know what they want to say, but forget some of the words necessary to convey this information. It is also common for person with TBI to confuse similar sounding words and not even to realise that they are doing so. Being unable to recall everyday words is termed “anomia” and everyone experiences it occasionally, but for the person with TBI anomia can be a constant burden. Anomic aphasia is one of the consequences of TBI, but a speech therapist can help by teaching strategies to deal with the difficulty (American Association of Health and Disability, 2009). Some of the participants struggled with the ability to communicate effectively and language impairment is one of the reasons.

The cognitive ability that is affected most during traumatic brain injury is speech. Participants indicated that since their brain injuries, their speech was affected the most. Four out of the 6 attendees indicated that their speech was severely affected after their experience of TBI. Participants 3, 7 and 8 point to this.

*“I also could not read, write or speak or even understand sometimes what people are talking and I always had to ask people what is this? What is that? And I could tell at times that they would be getting really frustrated and impatient with me sometimes, and it was also frustrating to me because before the accident I was clever boy but after the accident and the stroke all my cleverness was gone.”*

Participant 4 said:

*“One of the things that I am grateful for is that my speech was not affected as much like others here at Headway but I remember coming out of the hospital I got a gift which was a book instead of flowers or a card, a book by Robert Sharma and I read it and this mechanism helped me to not only regain but also sharpen my memory. But there are still events that happened years ago that I remember that will remind me that, by the way, you had a stroke, while there are things in my past that I do not even remember much.”*

This goes to show that the situation for each attendee is different and that each case should be treated from its own perspective.

### **Physical challenges**

During the interviews with the participants they all stated that after their brain injuries they experienced a lot of physical challenges such as the inability to walk, stand or even control their bowel movements. For some of the participants this was more severe than for others. Participants mentioned that an inability to walk was another challenge. They were unable to perform any daily tasks independently without the help of a caregiver,

from the smallest tasks such as using the toilet to the everyday ordinary activities such as walking. For, example, Participant 3 indicated that *“since I am wheelchair-bound, I am dependent on my caregiver.”*

Participant 6 shared some of the physical challenges experienced.

*“I could not walk and still struggle with my balance till this day. That was one of the hardest situations for me because then I had to be constantly dependent on other people, my family, to be helping me with all activities and that is one of the frustrating and hard things about being brain injured, and you are like a small child that needs to be carried everywhere and every time.”*

Participant 1 said:

*“First I had to go to Rehab because when I first came here I was still in a wheelchair. I could not walk by myself, I was like a child now. I could not even go to the toilet by myself I had to wear kimbis [nappies], I could not eat by myself but now I can even go to the toilet by myself. I had to cry to God all the time because I was just a thing, I could not believe I was just a thing that had to be picked up, I was just crying all the time, I could not cry in front of my mom. I would always cry on my own and no one would see me cause my mom already been through so much.”*

Not only are the individuals with brain injuries affected but so are their family members. Family members or caregivers need to assist with some tasks the survivor is unable to perform. Caregiver 3, for example, stated:

*“Another challenge is that especially after he came back from the hospital, we had to carry him and it was difficult because we are a house full of females and we really did not have that extra helping hand and help and because I do not work I had to look after him most of the time. It was just a lot of work and it is stressful on him and on us the people taking care of him.”*

Although all of the above-mentioned situations are a massive consequence of traumatic brain injury, some of the challenges are minimised through rehabilitation.

## **Theme 2: Stigmatisation and stereotyping of people with brain injuries or disabilities within communities**

This section discusses the perceptions that people have about disabilities as traumatic brain injury results in lifetime disability. The aim is to generate understanding in communities about traumatic brain injury (disabilities), by also considering how the survivors of brain injury are affected by these stereotypes and the discrimination against them.

### **Stigma or discrimination associated with traumatic brain injuries**

Stigma differs from discrimination: discrimination is unfair treatment because of a person's identity, which includes race, place of origin, sex, sexual orientation, age, family status or disability. Stigma refers to the degrading attitude of society that discredits a person or a group because of an attribute (such as an illness, deformity,

colour, nationality, religion). According to Miller (1993), more often than not individuals with brain injuries feel excluded from the day-to-day activities happening in society, such as access to job opportunities or the ability to access certain structures because of a lack of accommodative infrastructure to meet their special needs as individuals who are differently abled. Participant 4 mentioned:

*“Ya, people feel sorry for me because when they see me they do not see a normal person, but I see a normal person and the fact that people think that does not make me feel good at all because I am perfect, I am still a perfect person, I can still do anything. At first it was hard, but now I really appreciate myself and have appreciated. Although I do not do the things I did before, I still appreciate myself and I still have hope that I will be a perfect person tomorrow.”*

Participants shared the view that people often label them and used derogatory and demeaning words or phrases. Participant six said:

*“People will look at you like there is something wrong with you, of course, yes there is something wrong with you and my brother, my older brother, he’s a drunkard, he used to call me ‘sgole’ (disabled person) sometimes, and so my mom would be so angry about it, but you know what I have never been so angry about it. I just say my God I hope you can hear what he is saying about me, to me.”*

Such language used to refer to survivors of brain injury affects their self-esteem and confidence, but also the degrading terms are very offensive to human beings who are differently abled. Approaches by community members show a level of insensitivity, such as Participant 1, for example, referred to:

*“While other people will come bump into you on the streets and ask hawu sowu so wena sowu nje? (You are like this now, is this how you are now?) and I will just say to them: don’t worry maybe tomorrow it’s going to be you, cause now I know everything about disability and it comes even when you don’t expect it. It comes just like that and anything can make you be disabled.”*

Community members often would label and categorise individuals with disabilities based on the way that they look, talk, or any other physical characteristic that will often be distinguished as abnormal in society. The categorisation may be based on the lack of information available within TBI local communities. This is something most of the attendees felt still needs to be dealt with through education and providing knowledge to community members.

Participant 7 shared the opinions of community members after her daughter had suffered a brain injury, which is a clear indication of the lack of knowledge in communities about brain injury.

*“People with a brain injury are affected by these stereotypes from people in our communities because they are unable to get the necessary help as soon as possible, because people stay denying the truth about the disability and blaming the disability on witchcraft beliefs. Like my daughter, she was a dancer and she*

*was always busy with her life with this and that, and people will say that is why she is like this now, because people bewitched her and I would say ehhhh ehhhh she is like this because there is a purpose of why she is the way she is now and I do not believe in such things in life.”*

All of the above points show that individuals in our communities/society do not have the necessary or relevant information about individuals with brain injuries and indicate how important it is for communities to be educated about disabilities associated about brain injuries.

### **Theme 3: Families, communities and the government’s responsibility to improve the lives of people living with a disability**

Participants/survivors of brain injury were asked what they thought the family and the community could do to make the lives of individuals with a brain injury easier? Participant 4, for example, shared some of the aspects that the family can contribute towards helping and contributing positively to the journey of the survivors of brain injury.

*“I think families should be open more to learning about brain injuries and from there they can be better equipped to be supportive to their families. They need to be educated and be more involved in the lives of their family members to be able to give them a lot of love and understanding because that is what we need.”*

It is necessary for family members to acquire the necessary knowledge about brain injuries, because they can be able to help them in the best manner possible. According to the American Association of Health and Disabilities (2009), one of the most important factors is ensuring that families or caregivers are educated enough about the type of disability that the family member has, so to be better equipped to provide the necessary help and support in helping the individual recover to their best potential. The level of moral support provided by families is also one of the major aspects during the rehabilitation process of survivors of brain injuries; all the participants stated that one of the important things that could be provided by families during the rehabilitation process to recovery is love, support, care, peace and understanding.

Participant 5, for example, said:

*“My child support is very important to us people with a brain injury, we also need a lot of love from our families so that we can also be able to love ourselves and they should always be there to help and to see to it that we are not stressed, so that we can be able to live a better life after all of this pain and hurt we have suffered in our lives.”*

Support structures that are important for survivors of brain injuries should include family members as well as community rehabilitation centres. One family member said:

*“As you can see most of them are disabled. It is important that communities treat and accept them as human beings and they should not exclude them because they are different and treat them like human beings. Especially in*

*communities like here in Alex, people will laugh at you and gossip and all sorts of things that will make you small and they forget that tomorrow it could be them, you know. Batho (as people) we need to start seeing people who are disabled like any other person and we need to learn that's all that we can do, so we can be able to have the information that we need."*

This indicates that even people with disabilities, more specifically in this case focusing on individuals who are survivors of brain injuries, need to be treated as normally as possible. This is also a way of fighting against the stigma and the discrimination associated with disabilities in our communities. The lack of knowledge among community members could also contribute to their negative attitudes and the survivors' most emphatic suggestion is that community members should be educated.

A family member mentioned that:

*"The government firstly need to start investing more in place like Headway, you know. What we need more places like these because Headway on its own is too small to be able to accommodate the number of people with brain injuries just in Alex alone nje. And also at least the government is trying with the disability grant, you know. One can use it to live and it helps and that is one of the many ways that the government can help with and I feel like the government needs to create more education platforms of educating these people in our communities about brain injury. They need the information a lot but also policies that are to protect people with brain injuries to help these people who need the help the most. Some they do get better at some point. Maybe job opportunities can be made available as well, you know; they still have families that they need to support some of them."*

Participant one said:

*"I think there must be a good place for these people in the public; there are places that some of us, like those in wheelchairs, cannot access, but they should make them for us. The government should provide us with an income since most of us cannot work and more places like this one. The government should be active in helping these people and trying to change their lives for the better. Open opportunities for us."*

The government is the biggest contributor to ensuring the wellbeing of the individuals who are survivors of brain injury, through ensuring that the lives of people living with a brain injury are improved to make them better functioning human beings. All suggestions made are directed towards helping attendees find ways to discover their full human potential.

#### **Theme 4: Effectiveness of the rehabilitative services provided at Headway**

All the participants agreed that the services offered to them by Headway caregivers were effective in helping survivors recover during their rehabilitation process. Headway was able to provide support structures and services ranging from individual and family

counselling, speech therapy, occupational therapy, physiotherapy, companionship, skills development, linking them to other organisations and educational platforms.

One participant said:

*“First I had to go to Rehab because when I first came here I was still in a wheelchair. I could not walk by myself, I was like a child now. I could not even go to the toilet by myself. I had to wear kimbis (nappies), I could not eat by myself, but now I can even go to the toilet by myself. I had to cry to God all the time because I was just a thing. I could not believe I was just a thing that had to be picked up, I was just crying all the time, I could not cry in front of my mom. I would always cry on my own and no one would see me, cause my mom had already been through so much.”*

Another said:

*“A lot, hey, a lot – if it was not for headway William would not have improved the way that he has and not only did they help him but they helped us as a family, because I know that they have family meeting or workshops once every Saturday and family members come together to learn more about brain injuries, but to also be able to gain the understanding of how to deal with individuals with brain injuries in the home, so to be able to better help them improve. This place has been a blessing to my family and maybe to other families as well.”*

Participants acknowledged that the services provided at Headway have benefited them in more ways than one. Headway is providing a service that is necessary to help them recover to their full potential, but also serves as a platform to provide the necessary therapy using a holistic approach, instead of focusing on one aspect of the individual and also taking into consideration some of the systems affecting or impacting on the individual. The assistance involved either the family, government institutions such as clinics, hospitals, SASSA, or any other social services organisations that they need access to, so to be able to get the necessary help in recovering to their fullest potential.

When interviewing the TBIs and their families, it became evident that prior to their exposure to a traumatic brain injury, they had no knowledge at all of what brain injuries are. This proved to be a major problem as they found it hard to come to terms with the challenges. Being a survivor of traumatic brain injury comes with several challenges and consequences. One of them, perhaps the hardest, is the ability to be able to accept the current drastic change of self. Survivors of brain injuries struggle with the emotional battle of their lives and the ability to come to accept that their lives will never be the same. The fact that they suffer from a traumatic brain injury means a lifetime of disability regardless of rapid recovery during the rehabilitation process.

Survivors also struggle with physical changes after traumatic brain injury, such as the inability to walk, stand, control bowel movement, loss of speech, hearing and eyesight, to mention a few. Even though participants interviewed were being rehabilitated, the ability to adjust to a new life meant that they constantly depended on others for help. It

is part of an overwhelming journey for most, with mixed emotions of self-blame, hurt, anger, sadness and at times stress.

Challenges are not only limited to the emotional and physical aspects, but every single one of the participants indicated that they struggled to adjust to society and become a part of the community they came from; these are the psychosocial challenges experienced by survivors of brain injury. All attendees interviewed expressed the view that they are unfit to go back to the workplace and this was also stipulated in their medical records. Financial challenges were also a consequence of traumatic brain injury, as they now had to be dependent on the disability grant or the old age grant, with four of the six being on the disability grant and two on the older persons grant. Consequently, this has an impact on the family structure, especially for those who were breadwinners or whose families are unemployed. These challenges constantly affect the poverty-stricken families in Alexandra.

Furthermore, challenges are associated with perpetual stigmatisation and discrimination in the communities and the constant name-calling and labelling. The exclusion of individuals with disabilities from institutions like the work place, strips them of their human dignity and the ability to develop to their fullest human potential. In my view, it is important that society, families and communities are all educated about brain injuries and how they can affect an individual's daily living. Education about brain injuries is important to empower community members so that they can learn and develop the skills to take care of and approach individuals with brain injuries. Through exposure to education community members are also able to learn preventative measure on how to live a healthy and safe life to avoid the occurrence of brain injuries.

Participants reported that services provided at Headway are helpful and effective, as they would otherwise not be where they are in terms of their recovery. They further mentioned that Headway provided them with the possibility of a better life and the hope that they need to survive and to overcome all obstacles. All members confronted different challenges during their journey as survivors of brain injury and as family members having to be caregivers to survivors; but it was through the hope, love, understanding and light provided by Headway they are able to look forward to the future and work towards bettering all aspects of their lives; they have also come to appreciate life in more ways than one, as Headway provided them with life again and the joys of living as they have shared it with others.

## **CONCLUSIONS**

The study reported the challenges facing survivors of traumatic brain injury – challenges that can be physical, emotional, social and even financial. The challenges affect all parties involved during the rehabilitation process of the survivor. One of the biggest challenges shared by the attendees/survivors of traumatic brain injury is the stigma associated with disabilities in communities, but they also mentioned the discrimination in the structures and systems in our society. All the stigma and discrimination within their different spaces makes it hard for them to be able to become a part of society again, as they feel excluded, in turn leading to a sense of isolation.

Lastly, participants shared their views on some of the initiatives that could be taken by the government to make the lives of people living with brain injuries easier, such as being more involved in campaigns to facilitate opportunities for them to develop to their fullest potential. All participants felt that there could maybe be more involvement from the government on campaigns addressing brain injuries as much as they are involved in other campaigns such as dealing with HIV & AIDS, cancer, crime, etc. Brain injuries are just as important as any other social issue in our communities.

## **RECOMMENDATIONS**

Based on the conclusions, the recommendations are presented in three sub-sections below.

### **Recommendations to family members**

Family is the most important system in the recovery of individuals with brain injuries. Therefore, it is of importance that they also acquire the skills and knowledge of how they can better take care of their loved ones. It is of the utmost importance to develop coping skills during this overwhelming circumstance of being a caregiver to an individual with a brain injury who requires constant care and attention. Family members need to be active agents and involved in the rehabilitation process of their loved ones by providing them with love, support, respect, care and understanding and being patient with them during this challenging journey.

### **Recommendations to Headway**

According to the researcher's observations and findings from the focus groups, Headway as an organisation has been doing a remarkable job accommodating and catering for the needs of the individuals who are survivors of brain injury as well as helping their families. Their interventions are mostly individual directed at the individuals, with very few are catering for the family and the community; it is important for them to build more initiatives directed towards the skills development and training of family members as they can also adopt some of the rehabilitative strategies within the home. Family members should be involved to their maximum capacity since they are the primary caregivers of the survivor and they need all the knowledge necessary for them to be effective and competent in this task.

One of the other aspects that could be improved is also focusing on more skills development and training for some of the attendees, such as learning computer skills, physical and practical labour within their capacity, so as to better prepare them for the future if they could ever be ready to become part of the world of work. Some of the survivors need to know that there is life after brain injury and Headway, and be able at some point to terminate the service offered so that the individuals can be able to function independently on their own.

### **Recommendations to the government**

The government is one of the most important systems in the recovery process of individuals with brain injury and its policy interventions and implementation are important to ensuring that these individuals recover to their fullest potential. One of the



strategies that could be recommended to the government is building more facilities such as Headway so to be able to accommodate the large number of citizens with brain injuries. These policies must ensure that individuals with disabilities are also provided with the same opportunities just as much as other members of society through the provision of employment opportunities, so that they could also contribute to the country's economy and in this way inevitably contribute towards lowering the rate of poverty in our communities. Lastly, most of the participants in the study live in an area with poor infrastructure which is neither safe nor accommodative to their needs; it is important for the government to provide them with proper housing to accommodate their needs and levels of mobility. The government should be an active participant in creating awareness, distribution of knowledge and the provision of services and resources to survivors of brain injury so as to have a positive impact on their lives.

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